

For further information about carers' rights and about help and support that may be available, contact:

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CARERS Northern Ireland
the voice of carers

Equality Commission

FOR NORTHERN IRELAND

A PICTURE OF CARING



CARERS' STORIES

Foreword

The Equality Commission is delighted to work in partnership with Carers Northern Ireland to tell the stories of eight inspiring individuals.

Each highlights the significant issues that affect the life experiences of carers which are over and above their own day-to-day responsibilities. Caring for a loved one can be a source of great fulfilment. But a caring role can, over time, take its toll by having a negative impact on pensions, earnings, savings and career opportunities – with inevitable consequences in later life.

The Commission recognises this and is committed to supporting all carers. We do this through our work with policy makers to ensure they take on board their duties in relation to people with dependants under Section 75 of the Northern Ireland Act and we are also recommending increased protections as part of our legal reform agenda.

I would like to thank all of those who have shared their stories which reveal some of the important things in life, the constant heart and loving hand.

Bob Collins
Chief Commissioner ECNI

Any one of us could become a carer when disability or chronic illness hits our families, and our lives would change dramatically.

Carers give so much to society yet they risk poor health, social exclusion and poverty because of their caring role. This booklet is a glimpse into the lives of just some of Northern Ireland's 185,000 carers. All of them are unique individuals, in a range of different caring relationships.

The value of carers' unpaid work in Northern Ireland is £3.12 billion, and it is carers who are paying the cost. They should be able to care for others without damaging their own health and wellbeing. I hope this booklet will encourage readers to recognise the value of caring, and to support carers' right to have the same chance as anyone else of an ordinary life.

Margaret Campbell
Chair, Carers Northern Ireland

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner.

Carers' Rights

Although carers have few 'hard rights' in law there are some pieces of legislation it is useful to know about.

Rights in community care:

Carers and Direct Payment Act (Northern Ireland) 2002

This gives carers the right to an assessment of their support needs by Health and Social Care Trusts, who can then make services available if needed.

It also recognises children adversely affected by caring responsibilities as 'children in need' under the Children Order.

Rights in Work:

Employment Relations (NI) Order 1999

This gives rights to emergency dependant's leave to deal with a crisis in caring.

Work and Families (NI) Order 2006

This gives the right to request flexible working for carers.

Broader rights

Human Rights Act 1998

Carers, like everyone else, are entitled to rely on the protection of the Human Rights Act. Public bodies must take account of carers' human rights when they provide services, and seek to uphold these.

Northern Ireland Act 1998

Section 75 of the Northern Ireland Act requires public bodies to promote equality of opportunity for carers when developing policies.

Anti-discrimination law

In some cases carers may also have rights under disability and sex discrimination legislation.

Aileen's story

Aileen lives in Newtownards with her three children: Rebecca (6), Adam (9) who has severe autism and John (11) who has ADHD and dyspraxia. For three years she also cared for her husband Derek, who sadly died in 2009 from a brain tumour.

My caring journey started six years ago, when Adam was diagnosed with autism. He still needs a lot of attention and hands-on help with personal care. He has speech and communication difficulties and also emotional and behavioural problems that are very hard to manage at times. John was then diagnosed. He also needs help with feeding and cleaning himself, and has real problems socialising and concentrating, so he needs a lot of support too.

My worst time was probably about three years into full-time caring. My husband Derek had treatment for a brain tumour that had been causing seizures, and seemed to be improving. Then I went out for a walk and was knocked down by a car. I was severely injured, and although I have recovered well, I have been left with long term mobility problems. I had only just got back on my feet, with a metal frame on my leg, when Derek had a relapse.

It must sound like we're a disaster of a family, but we've got through by all helping and supporting each other. I am the main carer, but the children all help and encourage each other – John is terrific with Adam – and they support me as well. I've also met some lovely people, other carers, through a local carers' support group. It really helps to know you're not alone.

The main problems I have because of caring are all to do with my own health and well-being. The accident left me with permanent disabilities, and the physical and emotional strains of caring can take their toll. Your own health can go down while you're busy looking after everyone else.

If I had one piece of advice for other carers, it would be to look after yourself as well as you can. Taking care of yourself may feel selfish, but it isn't. After all, if you fall apart, everything else will fall apart around you.

Approximately 30,000 people in Northern Ireland
care for more than one person

“I am the main carer, but the children all help and encourage each other”





“...to be responsible for the health and well-being of someone you love, that’s scary”

Anita's story

Anita Mukherjee lives in Enniskillen with her husband and her son who is in his early 20's and was badly injured in a road traffic accident.

When my son was injured, I found out that your whole life can change in a moment. Before the accident, I knew nothing about head injury or disability – I never needed to. I have learnt so much since becoming a carer.

The main thing I have learnt is that healing the physical injuries is hard, but it's not as hard or as long a process as healing the mental and emotional trauma. And the same is true for carers. At the beginning, caring for my son was very physically demanding, tending to his day-to-day needs, but as he has begun to recover physically, what has been more difficult is helping him to come to terms with the mental injuries. You can't see the mental scars on the surface, and that makes it more difficult for other people to understand them.

The other striking thing about caring is how much responsibility you are taking on for another person. If you make a bad decision about your own health, that's one thing, but to be responsible for the health and well-being of someone you love, well, that's much more scary. I make sure now that I keep myself as fit and healthy as possible, because I need to be around for my son.

I think that my background, coming from India, has made me more resilient. I grew up expecting that I would have to work hard to overcome obstacles. I have encountered nothing but help and support from health and social care professionals, although sometimes I had to educate them about my son's cultural needs or reassure them that I understood everything that was going on.

I think it's really important for carers to get together to support each other, and to talk about their lives, so other people (including other family members) will understand the pressure and the responsibilities that caring involves.

I have had to put my own career and my own hopes on hold, but I'm happy to do this for as long as my son needs me. I don't complain about the petty things in life, because now I know what's really important.

One quarter of all carers provide over 50 hours of care per week.

Aoife's story

Aoife (13) lives in Belfast with her mum Anne (53) and dad Sean (58) who suffers from a form of dementia. She also has an older brother, Sam (20).

There was a time when my dad was just like everyone else's dad. I remember he used to take me to my dance class, and then we'd go to the shop on the way home for an ice cream.

But then he started to change. He'd forget things, and he didn't seem to understand things any more. Sometimes he'd go out and wouldn't come home because he'd got lost – that was really scary.

The doctors told my mum he had Pick's disease, a form of dementia. It was a big shock. I don't think I've got my head round it, really. What it means is that, although he still looks like he always did, inside he's very different. He gets confused and stuck with things.

Mum works full-time and leaves the house before I do, so I look after Dad in the morning before I go to school. I get him a cup of coffee and then I make sure he knows where everything is for the day.

He's OK to be on his own, but we have to make sure he knows the routine, so I write down everything for him before I go, and make sure there's food for him. As I leave the house I run through what's happening and tell him I'll be back later. He goes to a day centre (a special bus service picks him up), or to art classes, but when I'm at school I worry about him, about whether he's forgotten what's happening or become confused.

As soon as I get home, I check that he's OK. He's always pleased when I get back because he doesn't really like being by himself.

It's funny really because when we're out we look like a normal family but the truth is different. There are two adults in my family, but it's my mum and me – my dad is the child we both need to look after.

I still love my dad as a dad, but it's different now. He can't help with my homework or give me advice or anything like that. If my friends call for me to go out, and my mum isn't home from work, I have to say I can't go – my dad needs me.



“There are two adults in my family, but it's my mum and me – my dad is the child we both need to look after”

8,352 children aged 17 or under provide care for an adult or another child in their household



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Brian's story

Brian O'Hagan lives in Newry with his wife and children and cares for his mother who has vascular dementia and is still managing to stay in her own home.

My mum had been living with dementia for some time when my sister, who was her main carer up till then, fell ill and couldn't carry on. We all knew that my mum wanted to stay in her own home, and had always hated the idea of a nursing home, so someone had to take over, and it ended up being me.

At the time I was running my own business. I had four employees, and the business was expanding. At first I was able to carry on, but mum needed more and more support. Once she began to wander, and needed more or less constant supervision, my involvement in the business became more and more part-time, and things began to falter.

Part of the problem was in the lack of support we got from social services at the time. Once we'd agreed to take on the caring for mum, it felt like social services then walked away and left us with everything. I was struggling and asking for help and being refused support, and I couldn't understand why.

Things began to change when I finally managed to get a Carers' Assessment from social services, and got some clarity about what I could do and what social services duties and responsibilities were. There's more of a partnership with social services now, which is the way it should be. My mum and I get help that backs up what I do and allows me to have a working life outside the caring role.

I've been able to find a business partner and a good manager, and am able to work part-time from home because of the social services support for mum. This combination has worked, and business is now flourishing again.

It's still not easy – there's not much room for anything except working and caring. It's impossible to do anything on the spur of the moment, but I know I'm doing what mum always wanted and that she's safe and well cared for and where she needs to be at the moment. I have no regrets.

In Northern Ireland, over 40% of carers are men

Emma's story

Emma McDowell is married and has two sons: Andrew (27) and George, her eldest, now 38, who has cerebral palsy.

I became a carer unexpectedly following the birth of my first baby. There were problems at the end of my pregnancy. George had a difficult birth, and was very ill afterwards, but it took a long time before we were finally given a diagnosis of cerebral palsy.

This diagnosis came with a long list of all the things George wouldn't be able to do and a warning that from now on it was my main job to look after this child. So I was George's carer from the start, but it was 21 years before I recognised the term. As far as I was concerned, I was George's mother, even though I knew I was different to all the other mothers.

After the initial shock, I threw myself into making sure that George fulfilled all his potential in life. I gave up my PhD, and following a suggestion by a physiotherapist, I took George to the Peto Institute in my native Hungary. We found that conductive education was incredibly successful for George, although it was very hard work for all of us, and meant the family spent long periods of time apart.

At the time there were very low expectations for disabled children, and low expectations of parents, and we had to be resourceful and determined to get the support that George needed. I was not treated as the expert I knew I was, and had to learn tactics for dealing with the system. I believe that carers' knowledge should be respected by the professionals.

One of my worst times was when my mother was very ill in Hungary. When I realised she was dying, I tried frantically to get back to be with her, but social services weren't able to find any respite cover for George at short notice, and so I couldn't be there. Back-up in an emergency would make a huge difference to carers' lives at times of stress.

My caring has come at the cost of an academic career, and it has long term effects – just look at my pension today! But caring has also made me a much stronger, many-sided person. I am more assertive, and I engage in public policy debate – I sat on the Civic Forum, for instance, to represent carers' interests. Yes, in some ways caring has restricted my life, but in other ways it has widened my horizons.

For 32% of carers, it took over 5 years before they recognised themselves as a carer, missing out on vital benefits and support as a result

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Laura's story

Laura Collins lives in Belfast with her son David, who has autism, OCD and other mental health difficulties.

I have been a full-time carer for the past 29 years. Having cared for five members of my family over this period, I have often been faced with many difficult and demanding situations.

Carers, whether young, middle-aged or elderly, can find themselves in it for the long haul. The average length of care-giving is around seven years, but parent carers have caring responsibilities for the whole of their lives. Carers contribute significantly to their families, but often at a cost unknown to themselves. We are being stretched in every direction.

The reality is that caring brings compromise: compromised health and physical well-being, compromised social well-being, comprised family economic well-being.

I always remember something I heard from another carer: "When a dog goes to sleep - it's got one ear up. That's what it's like to care for someone with depression." Never being able to relax has long-term detrimental effects on your health. Adrenaline is essential for coping in a crisis. However, the non-stop production of this fight-or-flight hormone, in response to changing and demanding caring scenarios, results in fatigue, poor health, and low morale.

In my particular caring situation, I have had periods where I have been caring for three people at a time. There just weren't enough hours in the day. I do not want to hit burn-out, but have come close on several occasions. I, at times, have demanded too much of myself. As I get older, I find I have to invest more in myself to continue in the caring role.

Carers in Northern Ireland need to be afforded more respite care. Too many carers are spending 24 hours a day in their caring role, and their own well-being and lives are suffering as a result. Services continue to be patchy, underdeveloped and not round the clock.

In order to be competent carers, we require information, respite, professional support and crisis help. I want to see holistic carer support provided to all carers. Caring is often a full-time job - but with no salary, no holidays, no training and very little support. We need greater recognition and protection.

People providing high levels of care (over 50 hours a week) are twice as likely to be permanently sick or disabled as non-carers

“...to be competent carers, we require information, respite, professional support and crisis help”



Stephen's story

Stephen lives in Ballymena with his young daughter Charlotte and his wife Gillian who needs 24 hour care.

We were living in England when Gillian went into hospital to have our first child. Gillian had a brain haemorrhage the day after Charlotte's birth and needed emergency surgery. She initially seemed to recover well, but contracted MRSA and, two weeks later, had a massive stroke and went into a coma. She spent nine months fighting for her life, and another four years in hospital.

Before this happened, I had a great job with British Airways. They responded very well, allowing me a year's leave of absence. When it was clear I wouldn't be returning to work anytime soon, they offered a number of options, including a 5-year career break. For me, looking after Gillian was a lifetime decision, so I accepted a redundancy package.

My parents brought Charlotte home to live with them, while I rented out the family home and followed Gillian round a succession of hospitals in England, seeking specialist treatment. I was missing my daughter, living in grotty flats and spending 90 hours a week at a hospital bedside. Not surprisingly, my own health suffered. I blanked out emotions as much as possible to protect myself from despair, but I also missed out on the joy that a new child should bring. I developed back pain, had operations for non-malignant melanoma and at one point became clinically depressed.

It took me two years to get a community care package put together in Ballymena that would allow us to live together as a family, with support from the wider family circle, alongside services from the local health and social care trust. I was determined that we would have a family life.

One of the hardest things about being a carer is that my whole life depends on the decisions and actions of others. If Gillian's care package hits a snag, even something as simple as a care worker getting sick, then everything else in my life can fall apart. I have so few rights as a carer and I feel very vulnerable about changes in health and social care personnel or policy. My experience and expertise is not always recognised and I am constantly having to assert my right to be involved in decisions about Gillian's care.

There have been many difficult times, but I don't regret any of the decisions I made. I've learnt about what's really important in life, and it's not the material things – it's family and the friends who stick by you when things get tough. With a good care package for Gillian in place, and a whole new outlook on life, I'm now training to be a social worker.

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61% of carers in Northern Ireland report having health problems

Jim's story

Jim Gibson (77) lives in Larne with his wife Lily and his son Jim (52) who has Down's Syndrome.

I already had one daughter when Jim was born. When the doctor told us Jim was 'a mongol' I didn't know what he meant. Then he told us Jim wouldn't live beyond five years of age, and I knew that our most important job was looking after this precious child.

Fifty-two years later, that's what we're still doing. We knew that Jim would always live with us, and having him has been a blessing in our lives. I really do believe that caring makes you a better, more understanding person.

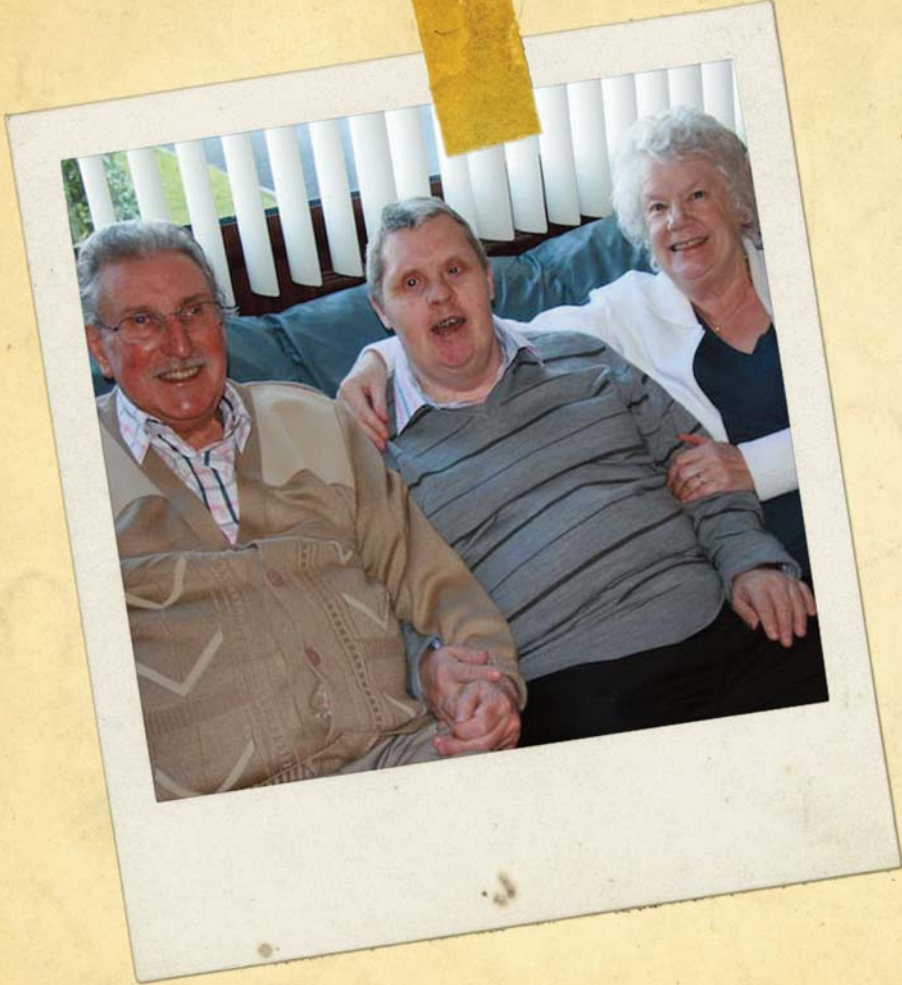
We've always worked together as a family. Originally my mother-in-law lived with us, and she helped my wife and I, especially when two more children came along. I worked until retirement, and during these years, Lily would have been the main carer. As we both got older, Lily developed macular degeneration and her sight is badly impaired, so I have taken on more of the caring role for both of them. But the three of us are a team.

The biggest strain has been the worry that you always carry with you. We almost lost Jim once, after an operation in his 20's, and so we are always watching him to make sure that he doesn't have any problems with his breathing or his swallowing, because those problems could turn serious so quickly. We have had good treatment from doctors and health professionals, which has helped.

Unfortunately I can't say the same about the benefits system. It sometimes seems like the whole system is set up to make it as difficult as possible. It feels like we have had to really fight, just to get the benefits we're entitled to.

We don't have social services support – we don't really feel we want it or need it, we'd rather cope as a family. But I was ill recently and things were very difficult for everyone. I've started to worry now about what happens if I get ill. It's strange to think like this, because as a carer your focus is always on the person you care for, not yourself.

The main carers' benefit is worth just £53.90 for a minimum of 35 hours – £7.70 per day



“...as a carer your focus is always on the person you care for, not yourself”